

# ASSISTIVE TECHNOLOGY COMMUNITY ALLIANCE OF NSW



MAXIMISING CHOICE  
AND CONTROL OVER  
ASSISTIVE TECHNOLOGY



# MAXIMISING CHOICE AND CONTROL OVER ASSISTIVE TECHNOLOGY

## Introduction

This paper presents the views of the Assistive Technology Community Alliance of NSW (ATCAN) on how to increase person-centred (or 'user centred') approaches in the provision of assistive technology (AT).

Assistive technology is a crucial enabler of choice and control for people with disability. As disability services undergo a transformational shift towards person-centred approaches, it will be important for organisations to take on systems and processes that demonstrate that the person is the primary focus. Traditionally, people with disability have found it challenging to explore AT preferences because their knowledge of what was available was not on par with Allied Health Professionals (AHPs) or AT suppliers. Additionally, cost drivers lead to pressure to preference 'stock items' over individualised solutions.

The clients of ATCAN members value the efficiency created by the streamlined processes of EnableNSW, which has created greater geographical equity in terms of the provision of services and some improvements in waiting times, especially for 'standard' items. However, members of ATCAN believe that this would be improved by increased focus on putting the person who uses the technology at the centre of their AT solution.

This paper will unpack the key elements of person-centred approaches and apply them in the context of AT. It is our hope that this document will serve as a guide to encourage best practice in the person-centred delivery of AT in NSW and provide some practical advice on what this looks like and how it can be done.

## About ATCAN

This paper was developed by NCOSS in collaboration with members of the Assistive Technology Community Alliance of NSW (ATCAN). This group is comprised of not-for-profit disability, community and welfare organisations, consumer and/or advocacy organisations with interest and expertise in assistive technology issues. The purpose of ATCAN is to;

- provide a forum for the discussion of issues relating to supportive equipment and assistive technology (AT) for people with disability in NSW, and
- undertake coordinated activities to improve access to supportive equipment and assistive technology as a basic right for people with disability.

The members of ATCAN are listed below:

- Aboriginal Disability Network NSW
- Assistive Technology Suppliers Australia
- Association for Children with Disabilities NSW
- Carers NSW Inc
- Cerebral Palsy Alliance
- NSW Council of Social Service
- Greystanes Disability Services
- Independent Living Centre NSW
- Northcott Disability Services
- Occupational Therapy NSW
- People with Disability Australia Inc
- Physical Disability Council NSW
- Spinal Cord Injuries Australia
- The Lymphoedema Action Alliance
- Vision Australia

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## Person-centred approaches

An oft-cited definition of person-centred approaches states they are:

“Ways of commissioning, providing and organising services rooted in listening to what people want, to help them live in their communities as they choose. People are not simply placed in pre-existing services and expected to adjust, rather the service strives to adjust to the person.”<sup>1</sup>

This means placing the person's needs, preferences and goals, as they define them, above those identified as priorities by others. The Victorian Department of Health<sup>2</sup> describes the elements of person-centredness as:

- Getting to know the client as a person
- Sharing of power and responsibility
- Accessibility and flexibility
- Coordination and integration of care by the service provider
- Having an environment that is conducive to person centred care both for the service providers and service users.

ATCAN encourages senior managers to take a lead in ensuring their service is person-centred, and that the culture, forms and processes of an organisation are responsive to the people using this service.

A person-centred approach does not of itself entail more expensive products and services. Rather, it involves attention being paid to the individual needs of each user. A long-term approach should be adopted. For example, although some titanium wheelchairs are more expensive than aluminium models, they are also more durable, and cost effective for users whose condition is likely to remain stable.

## The context

At all levels of Government, new policies and programs are giving people choice and control over their supports. For example:

- Under the National Disability Insurance Scheme (NDIS), people with disability are entitled to reasonable and necessary supports to enable them to have choice and control over their lives. We are pleased to see the National Disability Insurance Agency (NDIA) has recently released an Assistive Technology Strategy with a person-centred focus. ATCAN members applaud the inclusion of a participant capacity-building framework within the Strategy. This framework envisages that AHPs work with people with disability to assess their capacity in relation to AT, and develop a plan to improve capacity over time.
- With the rollout of Consumer Directed Care from 1 July 2015, people over 65 have also had choice and control over how they spend funding in their Home Care packages.
- The *NSW Disability Inclusion Act and Regulation* also encourage full inclusion in the system and processes of Government agencies; EnableNSW being a component of NSW Health.



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## CASE STUDY

A person-centred approach requires an understanding of the context within which the equipment will be used.

Under a 'reasonable and necessary' approach, luggage carriers fitted to the front of a manual wheelchair (pictured below) would be funded, because they are performing the function of an able-bodied person's arms while the wheelchair user's arms are providing propulsion (ie doing the job of legs). Such an inclusion to a wheelchair increases the independence of the person with disability.

ATCAN members understand that such items are not currently funded, being viewed as 'bags' to be purchased by individuals. This restrictive approach does not consider a person's needs in the context of their life and preferences.



*Flip down armrests allow some wheelchairs to carry belongings, increasing independence*



## Thinking about power

Three approaches to AT may be considered. These are the traditional, the functional and person-centred.

Traditional 'clinical' approaches to AT are associated with practitioner expertise, objective measurement and expectations of patient compliance with prescribed AT devices. The entrenched and legitimised professional power in these approaches is illustrated in the term 'prescription' to describe a professional's recommendation of an AT device.<sup>3</sup> Further, most AT provision models have been developed by service providers, informed by their perceptions and priorities.

Functional approaches to AT provision focus on consumers' abilities and environmental demands; and evaluating features of AT

devices against task requirements (where possible during trials in users' homes or workplaces). However, there is less focus on how the values and emotions of each user influences their use of AT.

Person-centred (or user-centred) approaches focus on the sharing of power between the user and professional. Power tends to be shared unequally if AT providers have competing objectives, such as individualised solutions and budgetary constraints. This tension is illustrated within section 34 of the *NDIS Act*, which mandates that a participant's supports need to assist them to achieve their goals, objectives and aspirations, while also representing value for money.

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The following table compares the models of AT provision:

	Clinical Approach	Functional Approach	Person Centred Approach
Who is the expert?	Professional	Professional	Individual (and allies)
What's the main aim of AT device?	Correct or reduce impairment	Help user perform required tasks	Help user perform required tasks in accordance with preferences
Role of client	Recipient of knowledge	Collaborator	Lead collaborator
Description of consumer experience	Prescription	Trialling	Shopping – where person has choice consumer rights and power.

## How to put the person at the centre of AT provision

### 1. Listen to what the person wants to achieve

The personal context of potential AT users contributes to differing experiences of AT acquisition and use. For example, injury, or a decline in function can indicate potential for AT use, but may be associated with grief or stigma, affecting the type of AT people will accept. In some cases, a person's cultural background may influence their preference of AT solutions.<sup>4</sup>

AHPs and AT suppliers should ask questions to determine an individual's goals, needs and preferences. A frequently-cited study from the USA found a lack of consideration for consumers' opinions in AT device selection to be a factor significantly related to AT device abandonment. Conversely, practices promoting a sense of control in users, can improve clinical and economic outcomes<sup>5</sup>

## CASE STUDY

### Choice and priority in action

A woman in her twenties purchased a child's electric wheelchair because the ability to fit under a table – which adult wheelchairs were too big to do – was more important to her than enhanced speed.

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Service reflections on listening to the person

Have you asked?	Why?
What is your previous experience with this technology?	This question determines level at which to 'pitch' to the user, and what questions to ask.
Tell me about your lifestyle? What outdoor and indoor environments are you using the device in?	Determines the user's needs, goals and preferences.
What expectations do you have about the technology?	It is important for users to have realistic expectations of the device or AT to avoid disappointment.
What about the device is most important to you?	Much of AT involves a compromise; for example, does the user value the size or speed of the device more?  It is important that users are involved with decisions and their priorities are primary. It is also critical that users are made aware of limitations or shortcomings of an AT solution.

## 2. The person using AT is the customer

Supplying AT involves a myriad of stakeholders, including the user, their allies, AHPs and often funding bodies. Suppliers walk a delicate line trying to satisfy all parties and in this process, the needs and preferences of the user can sometimes be diluted. If suppliers want to act in a person-centred approach, they need to put the wishes of the users first and foremost.

The internet has increased the ability of manufacturers to communicate directly with AT users, and should be utilised fully to spread information and enhance choice and control. Online resources should be supplemented with face-to-face information, the preferred communication method for many people with intellectual disability.

### Service reflections that will enhance responsiveness to the person's needs

Have you asked the person what they want and what tasks they are using the AT for?

Have you worked with the person to consider a range of options that could work in these environments?

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## 3. Knowledge is power; empower the user with knowledge

Growth and development of the AT market, in response to technological advances and population needs, increases the need for effective information dissemination to promote awareness among the population of potential AT users. Once aware of a user's goals and preferences, AHPs and suppliers should give the person options for comparison, emphasising the positive and negative aspects of each option.

Trials of AT devices in a person's home or workplace allow the person to gain first-hand knowledge of how the device will work for them. It may also be useful for professionals to link people with more experienced users of the technology, facilitating the sharing of knowledge and experience.

### Service reflections that will enhance a person's knowledge of AT options and uses

Have you demonstrated the full capacity of the device to the person who will use it?

Have you recommended devices the person might not be aware of which might help them achieve their stated goal and preferences?

Does the person have the capacity to trial equipment without the assistance of an AHP?

## 4. Make the person the centre of ongoing communication

ATCAN members are aware of people not informed:

- when original quotes and specifications are modified by funders or AHPs; and
- that they have been placed on a funding waiting list (and how long the list is).

There are current cases where communication informs people that they have 'prioritised', implying their order will be given immediate attention, when in fact there are three levels of priority, with waiting times ranging from 3 to 18 months.

Rephrasing this kind of communication can help a person to set realistic expectations of the status of their order and potential wait times. Under a person-centred approach, communication could be framed as outlined below:

"Because of your income and circumstance, your order has been placed in Category B. The average wait time for items in this category is 6 months." The inclusion of a follow up contact person's name and telephone number would be optimal and allow the person to gather any additional information they may require.



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Information is empowering. The simple step of including the person into all communications from AHPs, suppliers and funders concerning their purchase would improve information flow and demonstrate inclusive practice.

## Service reflections that will enhance a person's inclusion in ongoing communication

Is your communication in plain language, without jargon? Will the reader understand what you are trying to say?

Does the information include what the user needs to know?

- Are the anticipated timeframes clear?
- Does the communication indicate who to contact with queries?

Have you explained each step of the process?

Have you included the person in emails about delays, price/specification changes etc?

Is information about pricing (including any co-payment required) properly itemised?

Have you asked the person what form of communication works:

- telephone
- email
- letter

Has the person been told how to appeal a decision they disagree with?

## One size does not fit all

Person centred AT models suggest that the person's individual goals, needs and preferences should be considered before selecting devices however it has been observed that this is sometimes reversed in practice, where consumers acquire a device and then find their goals compromised or constrained.<sup>6</sup>

This is borne out by the experience of ATCAN members, who report that they sometimes face pressure to prescribe their clients 'stock' or re-issue devices, which may not optimally meet their needs. It is reported that a client can express dissatisfaction about elements of a device (for example size), if the first time they have seen it is at delivery, necessitating a complex adjustment process.



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We recognise that stock items can sometimes meet a user's needs. Adopting a person-centred approach, the user and their allies should be given information to make informed choices about using stock items compared to devices tailored to them.

## Service reflections that will enhance a person's knowledge of AT options and uses

Have you demonstrated the full capacity of the device to the person who will use it?

Have you recommended devices the person might not be aware of which might help them achieve their stated goal and preferences?

Does the person have the capacity to trial equipment without the assistance of an AHP?

## Methods of improving and facilitating person centred practice in AT

There are some basic steps that can be taken to ensure person-centred approaches are being delivered. These include:

- Asking the person about their preferences and providing them with information about possible options;
- Collaborate with the person when identifying objectives, planning and implementing solutions;
- Include the person in all communications about them;
- Encourage the person to bring a support person or advocate to appointments to assist them to articulate.

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## The costs and benefits of a person-centred approach

The following case study of a man from rural NSW illustrates that in addition to empowering the consumer, a person-centred approach to AT saves considerable time and resourced.

Actual Event	In person-centred practice
<b>February</b> Consumer assessed by an AHP undergoes a wheelchair trial with assistance from a Sydney based supplier.	The consumer receives a copy of the itemised quotation.
<b>June</b> Consumer receives notification from EnableNSW that he is eligible for funding, but is told he has to pay 1/3rd of the total cost.  Consumer writes to EnableNSW requesting additional information before committing to funding the shortfall.	An internal review assesses whether the decision to request a 33% contribution from the consumer aligns with a person-centred approach. If all options to meet their order without a large contribution are exhausted, the consumer is provided with a clear explanation of: <ul style="list-style-type: none"><li>• what will not be funded and why</li><li>• details of the appeal process; and</li><li>• an expected timeframe for delivery of solution.</li></ul> The above response would have likely answered any questions raised by the consumer in June.
<b>July</b> EnableNSW writes to consumer explaining funding shortfall.  Consumer (with help of AHP) challenges most of the reasons that items were not funded.  Additional equipment trials were conducted and further correspondence ensued between consumer, EnableNSW and AHP.	Not required if direct communication had occurred.  Not required if direct communication had occurred.
<b>November</b> Consumer receives written advice from EnableNSW that following additional information provided by the AHP his wheelchair will be fully funded, except for one item of low value.	Detailed communication about needs and preferences would have established funding at outset.  Consumer should be included in all communication.
<b>December</b> Due to the extensive delay from the initial assessment to placement of order, a further reassessment is conducted by the AHP and supplier prior to the order being confirmed.	A person-centred approach provides a greater level of detail at earlier stages and avoids repetition of processes.
<b>January</b> Consumer receives new wheelchair.	

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A person-centred approach would have involved including the consumer in all communication from the outset, informing them ahead of time of the items not to be funded, and centring these decisions on his needs and preferences, rather than a defined set of rules.

The table shows how this approach would have shortened the process considerably, saving time and resources for all involved.

## References

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